VICTORIAN ALCOHOL & DRUG ASSOCIATION

EFFECTIVE APPROACHES TO PREVENTION, DIAGNOSIS AND SUPPORT FOR FETAL ALCOHOL SPECTRUM DISORDER

Submission to the Senate Community Affairs Reference Committee

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VAADA Vision

A Victorian community in which the harms associated with drug use are reduced and general health and wellbeing is promoted.

VAADA Objectives

To provide leadership, representation, advocacy and information to the alcohol and other drug and related sectors.

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1. About VAADA

The Victorian Alcohol and Drug Association (VAADA) is a non-governmental peak organisation representing publicly funded alcohol and other drug services. In Victoria, there are approximately 100 funded alcohol and other drug services of different sizes located across the state.

VAADA aims to support and promote strategies that prevent and reduce the harms associated with alcohol and other drug use across the Victorian community.

VAADA welcomes the opportunity to submit to this inquiry. Fetal Alcohol Spectrum Disorder or 'FASD' represents a serious challenge for Australia's public health.

FASD refers to a range of conditions caused by pre-natal exposure to alcohol. FASD is a neuro-developmental disorder involving birth defects, growth and development deficiencies, impairments to vision and hearing, and other conditions. FASD is associated with a range of behavioural problems, comorbidities and poor social and life outcomes. These impacts are life-long. Crucially, FASD is a preventable condition determined by multiple and compounding complexities relating to social disadvantage.

VAADA makes the below submissions in respect to the inquiry

2. Summary of recommendations

Recommendation 1: Implement an ongoing national public education campaign about the risks of harm associated with alcohol consumption, including preceding and during pregnancy. This should be aimed at increasing levels of awareness *and* addressing prevalent social attitudes toward alcohol consumption.

Recommendation 2: Incorporate FASD and the harms of consuming alcohol while pregnant into healthcare professional guidelines and curricula. This should priortise GPs, obstetricians, midwifery and obstetric nursing, and specialist health workers (such as Aboriginal Health Workers).

Recommendation 3: Fund research into effective interventions for reducing alcohol consumption before and during pregnancy. Research focusing on innovative modes of primary prevention and behavioural change should be prioritized.

Recommendation 4: Fund the development of specialized resources on alcohol consumption during pregnancy and FASD for women belonging to priority populations. These should target women and other key members of these communities.

Recommendation 5: Fund the development and expansion of programs like the Positive Parenting Program for implementation and adaptation to broader audiences.

Recommendation 6: Commission research into best practice FASD education models, and fast track these for implementation across Australia's public education system, including in schools specialising in children with learning or other disabilities or complex needs. Develop FASD educational resources for private schools.

Recommendation 7: Establish a national FASD diagnostic service strategy to train health professionals on Australian FASD diagnostic tools and understand the importance of early diagnosis and intervention.

Recommendation 8: Fund and prioritise a range of diagnostic and screening models across Australia, with a focus on increasing diagnostic capacity in regional and rural areas and for other priority populations.

Recommendation 9: Develop protocols to ensure people at-risk of having FASD are screened when they come into contact with government services including criminal justice, foster care and child safety systems.

Recommendation 10: Ensure the *National Alcohol Strategy 2019-2028* and *National FASD Strategic Plan 2018-2028* are implemented effectively, evaluated and reviewed.

3. Recommendations

(a) the level of community awareness of risks of alcohol consumption during pregnancy

The National Health and Medical Research Council (NHMRC)[1] and the Australian Medical Association (AMA)[2] recommend that women abstain from alcohol consumption while pregnant. Pregnancy warning labels have appeared on some packaged alcohol beverages in Australia on a voluntary basis.

[1] NHMRC (2009) *Australian Guidelines to Reduce Health Risks from Drinking Alcohol*, Australian Government.
[2] AMA (2016) 'Fetal Alcohol Spectrum Disorder (FASD), *Australian Medical Association.*

In 2018, the Australian and New Zealand Ministerial Forum on Food Regulation made these warnings mandatory. The rollout of mandatory labels is currently in the process of being implemented.

The 2016 National Drug Strategy Household Survey (NDSHS) report — the latest for which detailed data is available — shows that around 35% of pregnant women aged 14-49 in Australia consumed alcohol while pregnant. While this figure includes alcohol consumption prior to knowing about the pregnancy, the rate of any alcohol consumption among women after knowing they were pregnant is still alarmingly high at approximately 25%. Further, research from 2015 estimates that at least 38% of Australian women continue to consume alcohol while pregnant.[3] Another paper estimated that between 60-80% of all pregnant women in Australia consume alcohol at some point during their pregnancy.[4]

This suggests that levels of community awareness of — and importantly *community attitudes* towards — alcohol consumption during pregnancy are currently having an inadequate preventative effect. This indicates that levels of community knowledge are not as important as the orientation of community *attitudes*. As results from the 2016 *National Drug Strategy Household Survey* show, those who engage in any sort of 'risky drinking' (estimated to be at least 25% of the population) are more likely to believe they can consume above the recommended guidelines without being affected or putting their health at-risk. Such beliefs are likely to shape attitudes and behaviours among women who are pregnant or are trying to become pregnant.

VAADA supports the introduction of mandatory warnings on packaged alcohol regarding drinking while pregnant. However, awareness and promotional activities that focus on social attitudes towards drinking are needed, while media that promotes the normalization of alcohol (i.e. advertising in sports, on social media and others) should be more tightly regulated.

Recommendation 1: Implement an ongoing national public education campaign about the risks of harm associated with alcohol consumption, including preceding and during pregnancy. This should be aimed at increasing levels of awareness *and* addressing prevalent social attitudes toward alcohol consumption.

[3] O'Keefe et al 2015) 'Prevalence and predictors of alcohol use during pregnancy: findings from international multicentre cohort studies', *Obstetrics and Gynaecology*, *BMJ Open*.
[4] Muggli et al (2016) '"Did you ever drink more?" A detailed description of pregnant women's drinking patterns', *BMC Public Health*, vol. 16(683).

(b) the adequacy of the health advice provided to women planning a pregnancy, pregnant women and women who are breastfeeding, about the risks of alcohol consumption

Troublingly, research shows that rates of FASD are higher among some vulnerable populations – Indigenous Australians, those living in remote areas, and those with low levels of education or living in poverty.[5] However, though higher educational levels did predict better knowledge of harms, they did not predict attitudes.

This suggests that despite guidelines regarding drinking during pregnancy, the practice enjoys a level of social acceptance across demographic cohorts in Australia. Given the widespread social acceptance of alcohol consumption in Australia, higher levels of awareness are needed *across demographic populations* to reduce positive attitudes toward alcohol consumption generally and during pregnancy.

Mandatory warnings on alcohol labels are a start. However, both broad and targeted messaging are needed to reduce existing and prevent further harms associated with FASD in Australia. Further, funding of evidence-based interventions to reduce drinking during and preceding pregnancy should be prioritized. Research into effective preventative interventions should be prioritised.

Recommendation 2: Incorporate FASD and the harms of consuming alcohol while pregnant into healthcare professional guidelines and curricula. This should priortise GPs, obstetricians, midwifery and obstetric nursing, and specialist health workers (such as Aboriginal Health Workers).

Recommendation 3: Fund research into effective interventions for reducing alcohol consumption before and during pregnancy. Research focusing on innovative modes of primary prevention and behavioural change should be prioritized.

(c) barriers that may prevent women receiving accurate, timely and culturally/ethnically appropriate information and advice on alcohol and pregnancy

While evidence suggests that accurate, timely and accessible information may not be getting through generally, Aboriginal and Torres Strait Islander women and women from CALD or regional and remote communities are likely to face additional barriers. Such barriers may include information not being available in language spoken at home, being delivered through culturally inaccessible or inappropriate means, or being geographically inaccessible. As such, these groups will require prioritized access to resources and supports.

[5] Elliott (2015) 'Fetal alcohol spectrum disorders in Australia – the future is prevention', *Public Health Research & Practice*, vol. 25(2).

This information should not be limited to broadcast methods. Instead, targeted information campaigns that are culturally appropriate and accessible are needed. This includes peers and bi-cultural workers, general practitioners and specialist medical professionals (obstetricians, gynecologists, maternal health nurses, and so on), community elders or leaders, advocacy groups and pregnancy/maternity support services and groups. Information (and support to understand it) need to be available in spaces already accessed by the women in these groups.

Further, some women may face challenges around accessing information due to low levels of education, or by having information filtered through a husband, male spouse or other family members. To minimize the risk of this, specialist spaces and consultations restricted to pregnant women should be encouraged and prioritized as a means for the dissemination of health information relating to alcohol and pregnancy. In addition, specialty whole-of-community programs like the Positive Parenting Program should be prioritized with funding aimed at capacity building and implementation.[6]

Recommendation 4: Fund the development of specialized resources on alcohol consumption during pregnancy and FASD for women belonging to priority populations. These should target women and other key members of these communities.

Recommendation 5: Fund the development and expansion of programs like the Positive Parenting Program for implementation and adaptation to broader audiences.

(g) awareness of FASD in schools, and the effectiveness of systems to identify and support affected students

Children affected by FASD, whether diagnosed or not, are at increased risk of low educational outcomes including disengagement from school.[7] This is, in part, because the physical, brain-based disabilities that comprise FASD commonly manifest as behavioural problems. This presents a significant challenge for educational settings, where FASD symptoms may be responded to with punishment, or in some cases, isolation from the schooling system.

The educational challenges posed by FASD are not limited to affected individuals, but are experienced by classmates, family members, educators and schooling communities. FASD-affected individuals who

[6] Andersson et al (2019) 'For all families: Triple- P positive parenting program in remote Australian Aboriginal communities: a study protocol for a community intervention trial', *BMJ Open*, vol. 9(10).
[7] Millar (2017) Educating students with FASD : linking policy, research and practice', *Journal of Research in Special Educational Needs*, vol. 17(1).

experience other forms of disadvantage or belong to marginalised communities, are likely to face additional challenges. For example, the education available to them may not be culturally responsive or well-equipped to deal with students with complex needs generally.

An early pioneer in developing specialised education systems for FASD is the Winnipeg School Division, located in the Canadian province of Manitoba. This has informed best practice approaches to managing FASD in educational settings, such as strategies for including FASD-affected students in general educational settings as well as specialised, FASD-only classrooms. These approaches, combined with locally developed knowledge (i.e. the Marulu Strategy)[8] should be used to develop responsive systems and strategies for identifying and supporting FASD affected students, teachers and schools in Australia.

Recommendation 6: Commission research into best practice FASD education models, and fast track these for implementation across Australia's public education system, including in schools specialising in children with learning or other disabilities or complex needs. Develop FASD educational resources for private schools.

(h) the prevalence of, and approaches to, FASD in vulnerable populations, including children in foster and state care, migrant communities and Indigenous communities

Prevalence of FASD has not been systematically measured in Australia. However, a prevalence rate of 5% is considered plausible.[9] However, as with many preventable health problems, those belonging to disadvantaged populations are at greater risk of being affected by FASD.

Just as alcohol harms are heightened among those in living in rural areas and those in low socio-economic status cohorts,[10] FASD risk is similarly heightened among disadvantaged groups. One study estimated prevalence levels in Fitzroy Crossing – a remote townships in northern Western Australia – to be as high as 19%.[11]

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[8] Fitzpatrick et al (207) 'The Marulu Strategy 2008-2012: Overcoming fetal alcohol spectrum disorder (FASD) in the Fitzroy Valley', *Australian and New Zealand Journal of Public Health*, vol. 41(5).
[9] Joint Food Regulation System (2018) *Food Regulation Standing Committee Decision Regulation Impact Statement: Pregnancy warnings labels on packaged alcohol*, ANZMFR.
[10] Dietze et al (2009) 'Income inequality and alcohol attributable harm in Australia', *BMJ Public Health,* vol. 9(20).
[11] Food Regulation Standing Committee Decision Regulation Impact Statement (2018) 'Pregnancy warning labels on packaged alcohol beverages', *Joint Food Regulation System*: https://www1.health.gov.au/internet/fr/publishing.nsf/Content/C35B5AC81AED240FCA2581EE001B80B0/$File/Forum%20-%20DRIS%20-%20Alcohol%20Warning%20Labels%20on%20Packaged%20Alcoholic%20Beverages%20-%2024-10-2018.pdf

Further, young people who have experienced out-of-home care are at heightened risk of experiencing homelessness both within 12 months of exit and in their lifetime.[12] FASD, diagnosed or not, is likely to present additional challenges to young people in and recently out of out-of-home care.

FASD research in Australia has largely focused on populations with a high proportion of Aboriginal Australians. VAADA would like to emphasise that FASD is not a condition restricted to a specific population. While some populations experience increased risk and burden of FASD, these same populations are much more likely to experience other forms of social disadvantage and marginalisation. As such, while responses catered to specific populations are needed, addressing the systemic disadvantage faced by these groups would go a long way to mitigate both the risks and harms of FASD within these communities.

FASD is not a problem specific to Indigenous Australians, nor any other group. Furthermore, many of the groups who face increased risk of FASD — Aboriginal Australians, people with experience of homelessness, people with an experience of incarceration, and people who use alcohol and drugs — face significant stigmatisation in the public domain. The prioritisation of FASD as a significant public health issue for Australia should not be used as an opportunity to add to or capitalise upon this.

Importantly, research has shown that early diagnosis of FASD (<12 years) significantly reduces adverse life outcomes for FASD affected people.[13] As such, VAADA recommends that diagnostic and screening systems be increased, with prioritised access to those populations experiencing increased risk.

Recommendation 7: Establish a national FASD diagnostic service strategy to train health professionals on Australian FASD diagnostic tools and understand the importance of early diagnosis and intervention.

Recommendation 8: Fund and prioritise a range of diagnostic and screening models across Australia, with a focus on increasing diagnostic capacity in regional and rural areas and for other priority populations.

(i) the recognition of, and approaches to, FASD in the criminal justice system and adequacy of rehabilitation responses.

[12] Johnson et al (2010) 'Pathways from out-of-home care', *AHURI Final Report No. 147*.
[13] Streissguth et al (2014) 'Risk factors for adverse life outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects', *Journal of Developmental and Behavioural Pediatrics*, vol. 25(4).

While national figures for FASD prevalence in correctional settings in Australia are currently unknown, one study in Western Australia found the rate of among children in detention was 36%.[14] Globally, prevalence rates for FASD in prison populations are estimated at between 10% and 23% among youth detainees and approximately 10% among adult prisoners globally.[15] In Canada, youth with FASD are 19 times more likely to be incarcerated in detection centres compared to non-FASD youth.

Given the importance of keeping young people out of the correctional system, the capacity of the criminal justice system to divert FASD-affected individuals away from corrections and provide FASD-responsive rehabilitation to affected prisoners needs to be increased. There is a significant body of evidence supporting several educational, behavioural, psychological, pharmacological and nutritional interventions for FASD-affected individuals that can be adapted and applied to schooling, youth corrections and adult correctional settings.[16] [17]

Rehabilitation programs are currently available in Australian correctional settings. However, their efficacy can be difficult to determine. Program availability can be inconsistent and various aspects of prison systems can undermine their efficacy. Rehabilitation programs should be responsive to the needs of inmates with FASD as well as those with acquired brain injuries, learning disabilities and other forms of neurodiversity.

Recommendation 9: Develop protocols to ensure people at-risk of having FASD are screened when they come into contact with government services including criminal justice, foster care and child safety systems.

(j) the social and economic costs of FASD in Australia, including health, education, welfare and criminal justice

The economic costs of FASD have not been comprehensively measured in Australia. However, the federal Department of Health has estimated that a plausible incidence rate of 5% would cost the

[14] Bower et al (2018)'Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia', *Open BMJ*.
[15] Popova et al (2011) 'Fetal alcohol prevalence estimates in correctional systems: a systematic literature review', *Canadian Journal of Public Health*, 102(5).
[16] Chandrasena et al (2009) 'Fetal Alcohol Spectrum Disorders: An overview of interventions for affected individuals', *Child and Adolescent Mental Health*, vol. 14(4).
[17] Paley et al (2009) ''Intervention for people with fetal alcohol spectrum disorders: Treatment approaches and case management', *Developmental Disabilities Research Reviews*, vol. 15(3).

Australian community an estimated $1.18 billion per year. This equates to a cost of $75,661 per new case of FASD in Australia.[18]

The social costs of FASD are significant, though are difficult to quantify. A Canadian study from 2016 found that average life expectancy among people living with FASD was 34 years. Critically, the leading causes of death among those with FASD are external, including suicide, accidents, AOD poisoning, and mental and behavioral disorders, with congenital (internal) conditions accounting for a smaller proportion of total deaths.

Given the array of issues faced by people living with FASD, governmental responses must balance prevention with a focus on supporting those currently affected. A coordinated suite of responses across policy areas (health, education, welfare, criminal justice and rural/regional) are need to close gaps in support, messaging, information resources and interventions.

Recommendation 10: Ensure the *National Alcohol Strategy 2019-2028* and *National FASD Strategic Plan 2018-2028* are implemented effectively, evaluated and reviewed.

(p) any other related matters

VAADA is pleased that Australia's *National Alcohol Strategy 2019-2028* identifies FASD as a priority area.[19] The strategy identifies 'improved prevention through community awareness, and improved FASD detection, diagnosis and access to therapy.

However, VAADA is concerned that the strategy limits FASD prevention efforts to awareness raising activities. Regulatory interventions that reduce the availability of alcohol at the population-level and limit the availability of very cheap alcohol are likely to have a stronger preventative impact than awareness raising alone.

Evidence from Scotland on the impact of minimum unit pricing (MUP), has shown a reduction in the amount of alcohol purchased by households by 7.6% nationally. This equates to a reduction in alcohol consumption of 9.5 Grams of pure alcohol for each adult per household. VAADA strongly recommends that Minimum Unit Pricing be considered in Australia. This will not only reduce the risk of FASD across the Australian population but also reduce the prevalence of other wide-spread alcohol related harms.

VAADA is particularly pleased that Australia has a *National FASD Strategic Action Plan 2018-2028* and endorses its focus on prevention, screening and diagnosis, improved support and management, and

[18] Popova et al (2011).
[19] Department of Health (2019) *National Alcohol Strategy 2019-2028*, Commonwealth of Australia.

reduced stigma.[20] VAADA supports the recommendations in the Strategic Action Plan, particularly the focus on reducing alcohol access.

However, the Plan limits reductions in access to 'at-risk groups and communities'. Targeted access reduction is likely to have minimal effect, given the high rates of alcohol availability in Australia generally. Moreover, with advances in technology increasing access further (for example, online delivery services), any targeted restrictions are likely to be easily circumvented.

Further, targeted restriction of access risks creating an unfair system where vulnerable populations are targeted and excluded from what is a thoroughly normalized social pastime and activity. Intervention at the population level through controls such as pricing, limiting opening hours, and limitations on alcohol outlet density, would avoid the unnecessary and stigmatising targeting of specific groups while reducing alcohol-associated harms for all Australians.

The Australian Government should aim for a more balanced approach to alcohol regulation that ensures alcohol continues to be available and enjoyed moderately while reducing the harms associated alcohol saturation (extremely high levels of availability and access).

VAADA thanks the inquiry for its consideration and encourages the committee to be courageous in its recommendations. If VAADA can be of further assistance to the inquiry or the Committee, please do not hesitate to contact us.

[20] Department of Health (2018) *National fetal Alcohol Spectrum Disorder Strategic Action Plan 218-2028*, Commonwealth of Australia.